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ORIGINALES

Description of the Care Burden for a family with an elderly risk of dementia

Descripción de la Carga de Cuidado de una familia con un anciano en riesgo de demencia

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ABSTRACT:

Introduction: Dementia is one of the leading causes of dependence among the elderly worldwide and has a physical, psychological, social, and economic impact, especially on their families. Early recognition of the caring burden for the elderly at risk of dementia is important to prevent deterioration.
Objective: This study aims to obtain an overview of the care burden for the elderly at risk of dementia in the community.
Methods: This descriptive study involves a population of all the elderly living with their families in the Jakarta area with a random sampling of 168 respondents. The screening instrument for modifying the care burden of families consists of 21 items.
Results: Most elderly are at risk of dementia, accounting for 72%, 73.2% have a chronic disease, and 73.8% are still independently doing BADL. Furthermore, 58.3% of the families have a low burden of care.
Conclusion: The burden experienced by the elderly and their families influences their life quality. It is hoped that families with older members continue to improve and maintain their quality of life by remaining active and productive in fulfilling their needs and pleasures.

Keywords: burden of care for family, elderly, risk of dementia.

RESUMEN:

Introducción: La demencia es una de las principales causas de dependencia entre los adultos mayores a nivel mundial y tiene un impacto físico, psicológico, social y económico, especialmente en sus familias. El reconocimiento temprano de la carga del cuidado de los ancianos con riesgo de demencia es importante para prevenir el deterioro.
Objetivo: Este estudio tiene como objetivo obtener una visión general de la carga de cuidado de los ancianos en riesgo de demencia en la comunidad.
Métodos: Este estudio descriptivo involucra una población de todas las personas mayores que viven con sus familias en el área de Yakarta con una muestra aleatoria de 168 encuestados. El instrumento de tamizaje para modificar la carga de cuidado de las familias consta de 21 ítems.
Resultados: La mayoría de los ancianos están en riesgo de demencia, representando el 72%, el 73,2% tiene una enfermedad crónica y el 73,8% todavía está haciendo ABVD de forma independiente. Además, el 58,3% de las familias tienen una baja carga de cuidado.

Conclusión: La sobrecarga vivida por los ancianos y sus familias influye en su calidad de vida. Se espera que las familias con miembros mayores continúen mejorando y manteniendo su calidad de vida manteniéndose activas y productivas para satisfacer sus necesidades y placeres.

Palabras clave: carga de cuidado para la familia, adulto mayor, riesgo de demencia.

INTRODUCTION

The elderly population in the Jakarta area is estimated to increase by 5.13% between 2010 and 2035, from 9.6 million to 16.39% of the total population, which is 11.5 million. Likewise, life expectancy in 2010-2015 was 71.6 years and is expected to increase to 73.9 years in 2030-2035[1]. This shows that the increase in the elderly population is accompanied by increasing age.

According to the theory of functional consequences, changes in body function accompany increasing age[2]. These changes are caused by the aging process and the accompanying risk factors. The theory of biological aging explains the decline in cell function, which accelerate tissue damage and affects changes in the function of the human body system. The nervous system experiences changes in structure and function due to aging in the elderly, characterized by a decline in thinking and remembering processes.

The decline in the thinking and remembering process in the elderly is known as dementia. It is a collection of symptoms of cognitive deficits that are continuous and progressive, including the decline in memory, language skills, intellectual, and other brain functions. Therefore, they interfere with daily activities and are generally accompanied by behavioral and psychological changes[3,4]. It is also defined as a decrease in independence and at least one of the powers of concentration, learning, memory, language, daily activities, and the function of understanding the feelings and thoughts of others[5].

The prevalence of dementia increases with age. Various studies show that this incidence doubles every 6.3 years, from 3.9 per 1000 people yearly at the age of 60-64 years to 104.8 per 1000 people at 90 years and above[6]. Its prevalence in Indonesia in 2015 reached 1.2 million people, with an estimated increase to 1.9 million in 2030 and almost 4 million in 2050[7]. This makes dementia a health problem that can influence the life quality of individuals, family, friends, and the community.

Dementia impairs the cognitive and other abilities of the elderly, necessitating the assistance of family members to carry out their daily activities. The impact of this health problem and the time needed for treatment can cause stress and become a burden to their families. This is consistent with the results of a qualitative study that various cognitive and behavioral changes in the elderly can cause stress for their families[8]. Psychosocial responses that arise when caring for partners include anxiety and confusion, boredom and exhaustion, and positive responses experienced by caregivers are a sense of gratitude and resignation[9].

Other qualitative studies yielded several themes about family knowledge of dementia symptoms, including struggle and despair, family as a source of stress, limited knowledge and misunderstanding, not being diagnosed with dementia, and not comprehending medical care[10]. Families who care for the elderly with complex health

problems experience a high subjective burden. Some factors that play a major role in reducing the burden on families include health status, knowledge, caring satisfaction, and social support from the family[11,12]. Furthermore, reducing the care burden through social and formal support is a way coping skills can boost psychological resilience[13].

Family health can be affected by the care burden for the elderly with health problems. The elderly with disabilities often negatively perceive their health and become dependent. This is consistent with the opinion that caring for someone with serious cognitive problems can impact the welfare of their caregivers[14,15]. Furthermore, this situation can be surmounted by educating and preparing family, relatives, friends, and elderly observers to optimally provide care in a way that meets their physical, emotional, social needs social, and financial needs. Families providing care for the elderly must be able to address their physical, psychological, social, and spiritual needs[2,16]. This is supported by studies' results that people with dementia need care, daily activities, and social activities. Meanwhile, informal caregivers need social activities, information about dementia care and the health care system, and emotional support[17].

Dementia care for caregivers and support for the health care system are part of the WHO global action and the strategic plan for managing Alzheimer's disease and other dementias by the Ministry of Health, Indonesia. It is hoped that the prevention and treatment of people with dementia can be initiated as early as possible, starting from the family level. The family as a support system for the elderly is crucial to the application of this study's results. They can participate in providing services to the elderly and contribute to preventing and controlling disease risk factors.

Based on the existing problems and phenomena, this study aims to provide an overview of the care burden for families of the elderly with dementia risk in the Jakarta area.

METHODOLOGY

This is a descriptive study with a population of all families with elderly in the Jakarta area. Two areas were taken randomly to obtain a sample of 168 elderly in East and south Jakarta. The data collection tool is a modification of the Screening for Caregiver Burden, which consists of 21 items. This tool was used to objectively and subjectively measure the experience of the caregivers[11,18]. It used a five-point Likert scale (0-4), including "no experience", "there is experience but no difficulty", "there is experience with a low difficulty level", "there is experience with a medium difficulty level", and there is experience with a high difficulty level". The total score is 84, and the validity and reliability test results using Cronbach's Alpha is 0.888.

This study passed the ethical review from the Faculty of Nursing Ethics Committee, the University of Indonesia, with Number 46/UN2.F12.D/HKP.02.04/2018. It applied three basic ethical principles, namely respecting the dignity of others, not harming, and fairness. The consent of the respondent was obtained by the consent form voluntarily. All data is kept confidential and used for study purposes.

RESULTS

Table 1 gives a detailed description of the characteristics of the elderly. A total of 168 elderly people living with their families participated in the study. Most were 66 years at 61.9%, 65.5% were female, and 48.8% attained elementary school education. Most are capable of performing instrumental activities of daily living (IADL), such as using the telephone, shopping, preparing food, managing the house, washing, using transportation, preparing and taking medicine, and managing finances, accounting for 56%. Furthermore, 73.8% can carry out their daily activities (BADL) independently, such as eating, bathing, moving, going to the bathroom, urinating/defecating, and dressing. The examination of cognitive function status in the elderly was carried out using the Indonesian version of the Hopkins Verbal Learning Test (HVLT) instrument. The result showed that 72% of the elderly in the Jakarta area are at risk of dementia, as shown in Table 2.

Table 1. Distribution of characteristics of the elderly in the Jakarta area in 2020 (N=168)

Characteristics of the elderly	Frequency	Percentage(%)
Age		
60 – 65 years old	64	38.1
≥ 66 years old	104	61.9
Gender		
Male	58	34.5
Female	110	65.5
Marital status		
There are still a couple	71	42.3
Widow	84	50.0
Widower	13	7.7
Level of education		
No school	16	9.5
Elementary school	82	48.8
Junior high school	34	20.2
Senior high school	28	16.7
University	8	4.8
Have a chronic disease		
Yes	123	73.2
No	45	26.8
BADL		
Independent	124	73.8
Dependency	44	26.2
IADL		
Independent	94	56.0
Dependency	74	44.0

Table 2. Distribution of the elderly by cognitive function status using HVLT examination in the Jakarta Area in 2020 (N=168)

Cognitive Status	Frequency	Percentage (%)
Risk of Dementia	121	72
Normal	47	28

Table 3 describes the families' characteristics who care for the elderly. The most family age is late adulthood at 44%, 85.7% are female, and 73.2% are married. Furthermore, the highest education level is senior high school at 67.3%, and most families who care for the elderly are housewives, accounting for 72.6 %. Biological children mostly dominated the relationship at 71.4%.

Table 3. Distribution of families characteristics caring for the elderly in the Jakarta area in 2020 (N=168)

Family characteristics	Frequency	Percentage (%)
Age		
Adolescent (13-18 yrs)	5	3.0
Early adulthood (19-40 yrs)	41	24.4
Late adulthood (41-59 yrs)	74	44.0
Elderly (>= 60 yrs)	48	28.6
Gender		
Male	24	14.3
Female	144	85.7
Marital status		
Marry	123	73.2
Widow	9	5.4
Widower	3	1.8
Not married yet	33	19.6
Level of education		
No school	3	1.8
Elementary school	3	1.8
Junior high school	15	8.9
Senior high school	113	67.3
University	34	20.2
Current job		
Teacher	2	1.2
Self-employed	11	6.5
Laborer	5	3.0
Private sector employee	25	14.9
civil servant	3	1.8
Not working(Housewife/Retired)	122	72.6
Relationship with the elderly	120	71.4
Biological children	22	13.1
Children-in-law	10	6.0
Parent's brother	16	9.5
Grandchild		

Table 4. Distribution of the burden of caring for families with elderly at risk of dementia in the Jakarta Region in 2020 (N=168)

	Caring Burden Items	No experience		There is experience but not difficult		There is experience with the light difficulty		There is experience with medium difficulty		There is experience with the heavy difficulty	
		F	%	F	%	F	%	F	%	F	%
1.	I cannot control the disease that appears in the elderly.	70	41.7	49	29.2	38	22.6	11	6.5	0	0.0
2.	I cannot give influence/direction to the actions/ behavior of the elderly.	66	39.3	60	35.7	30	17.9	9	5.4	3	1.8
3.	The elderly always ask the same questions over and over.	42	25.0	80	47.6	36	21.4	7	4.2	3	1.8
4.	I have to do routine work like shopping, cooking, preparing food, and washing, which are usually carried out by the elderly.	36	21.4	93	55.4	27	16.1	10	6.0	2	1.2
5.	I feel sad because I cannot talk to the elderly.	97	55.7	50	29.8	15	8.9	5	3.0	1	0.6
6.	I am fully responsible for looking after our household.	22	13.1	99	58.9	33	19.6	10	6.0	4	2.4
7.	The elderly cannot cooperate with other family members.	85	48.8	55	32.7	24	14.3	6	3.6	1	0.6
8.	I have to look for / need help from other people / the community to pay for the treatment of the elderly.	114	67.9	27	16.1	16	9.5	7	4.2	4	2.4
9.	Seeking/asking for help from others is embarrassing and lowers self-esteem.	122	72.6	27	16.1	9	5.4	5	3.0	5	3.0
10.	The elderly often no longer recognize me all the time.	138	82.1	18	10.7	10	6.0	2	1.2	0	0.0
11.	The elderly once beat other family members and me.	154	91.6	10	6.0	2	1.2	0	0.0	2	1.2
12.	The elderly have urinated (wetting the bed) in bed.	134	79.8	21	12.5	6	3.6	3	1.8	4	2.4
13.	The elderly suddenly threw, attacked, and threatened other family members and me.	157	93.5	7	4.2	2	1.2	1	0.6	1	0.6
14.	I have to cover up the mistakes of the elderly.	109	64.9	48	28.6	7	4.2	3	1.8	1	0.6
15.	Dressing up/makeup and dressing the	124	73.8	37	22.0	4	2.4	2	1.2	1	0.6

	Caring Burden Items	No experience		There is experience but not difficult		There is experience with the light difficulty		There is experience with medium difficulty		There is experience with the heavy difficulty	
		F	%	F	%	F	%	F	%	F	%
	elderly every day makes me tired.										
16.	I tried to help the elderly, but he did not appreciate or thank you.	127	75.6	28	16.7	10	6.0	3	1.8	0	0.0
17.	I get frustrated when I have to look for things that are hidden/stored by the elderly.	108	64.3	41	24.4	14	8.3	5	3.0	0	0.0
18.	I am worried that the elderly will leave the house and disappear.	141	83.9	14	8.3	8	4.8	2	1.2	3	1.8
19.	The elderly have attacked other people, including myself and other family members.	157	93.5	6	3.6	2	1.2	1	0.6	1	0.6
20.	I feel alone, as if everything in the world I have to carry alone.	135	80.4	22	13.1	7	4.2	1	0.6	3	1.8
21.	I feel ashamed to take the elderly out of the house for fear that he will do something inappropriate/embarr assing.	157	93.5	8	4.8	2	1.2	1	0.6	0	0.0
	Average percentage		64.9		22.7		8.6		2.7		1.1

Table 5. Distribution of the burden of caring for families with elderly at risk of dementia in the Jakarta Region in 2020 (N=168)

Burden of care	Frequency	Percentage(%)
Low	98	58.3
High	70	41.7

DISCUSSION

The results showed that most of the elderly are female and over 66 years of age, with a 72% risk of dementia. This data is consistent with the result of a study that 66 years and above is significantly associated with the risk of dementia (p-value 0.026) and the elderly have a 2.7 times risk of developing the health problem compared to those aged 60-65 years[19]. An increase in life expectancy will increase cases of degenerative diseases, including dementia. Furthermore, an increase in the number of elderly will increase the need for health infrastructure[20,21]. The Elderly Posyandu, which is Integrated Service Post, is one of the effective health services established by the

Public Health Center program. It provides counseling about health problems for the elderly.

The majority of family members who care for the elderly are biological children, married, and senior high school graduates. Furthermore, the family is the best caregiver for the elderly and is also the smallest unit that has the power to influence society. It becomes the main target in realizing a healthy society through the healthy behavior of every member. Generally, the role and power structure of the family has a significant effect on public health[16].

The analysis showed that most of the average item scores indicated “no experience” with the 21 subjective and objective statements. Some of the items include: the elderly can still recognize their families, do not ask the same thing repeatedly, and the family does not feel ashamed to accompany the elderly outside. This shows that most elderly have not been diagnosed with dementia and can still carry out independent activities. Therefore, their care is not a heavy burden for the families.

The description of the statement items also shows that the majority indicated that they lacked experience caring for elderly at risk of dementia with high dependency levels. This is evident in some of their statements in table 4, such as the elderly do not recognize me often; they suddenly threw, attacked, and threatened other family members and me; “I feel ashamed to take the elderly out of the house for fear that they will do something inappropriate or embarrassing”. The statements above showed that most families do not have the experience. However, they can still take good care of the elderly without being a burden because they are yet to suffer from dementia. Feelings of frustration, worry, sadness, fatigue, shame, and feeling alone are mostly not experienced by the family. The results showed that the care burden for the family was still at a low level of 58.3%.

This is contrary to the results of a qualitative study, which showed that boredom and fatigue are the psychosocial responses that occur when caring for a partner with dementia[9]. Furthermore, negative aspects related to health services can be a burden for caregivers[22].

The analysis also shows that most of the elderly are still independent in carrying out daily activities in the form of BADL and IADL. The interview results also showed that some elderly do their hobbies, such as reading, gardening, sewing, and singing. They also carry out social activities such as recitation, social gatherings, and association, as well as operate their cellphone.

The high burden of care and chronic diseases suffered by the elderly must be a common concern because it negatively affects the quality of life and the family itself. Furthermore, the care burden for caregivers is related to family functions, such as social and emotional communication between members, thus, affecting the quality of life[23]. The burden of caregivers is a response to physical, mental, emotional, social, and financial stressors associated with providing care to members with chronic illnesses. Early detection of risk factors and the provision of health education and training on how to care for the elderly at risk of dementia are important.

Providing education and interaction in support groups can reduce the burden of caring for dementia patients[24]. These results are also supported by a study’s report that

health status, knowledge, care satisfaction, and social support from family are factors that play a major role in reducing the care burden[11,12]. Social and formal support can alleviate the caregiving burden, hence, coping skills become effective for increasing psychological resilience[25]. This is in line with the opinion of [26], which states that knowledge and understanding can raise awareness in a person and change behavior.

This condition causes the elderly at risk of dementia to require special attention and care from families and health care providers. The support of health workers is very important for sufferers and their families, especially in terms of providing information. This is because health education can improve health status, prevent additional problems, maintain existing status, maximize the functions and roles of clients during illness, and help clients and families overcome problems[26,27]. Unique sources of cognition are knowledge, awareness, understanding, or specific information about anything acquired from education and experience[16,28,29,30].

CONCLUSIONS

Families with elderly at risk of dementia have a low care burden because they are able to continue their daily lives independently and actively participate in social and religious activities. It is hoped that the family will continue to carry out regular checks related to chronic diseases and early detection of dementia to avoid increased symptoms. Similarly, families are expected to maintain physical and emotional conditions through support group activities such as health education.

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